

Admin, LACO

Subject: FW: End Of Life Submissions
Attachments: MH Mail 26 05 11.pdf; Journal.pdf

From: Nigel
Sent: Friday, 29 September 2017 3:42 PM
To: Joint Select Committee on End of Life Choices <eolcc@parliament.wa.gov.au>
Subject: End Of Life Submissions

Dear Sir/Madam,
Please find attached a self-explanatory letter sent to a number of newspapers regarding the death of my wife following long suffering with Alzheimer's. The last three years she was in a vegetated state and it was hell to see her suffer like this.

I have also enclosed a copy of my journal which will give an insight into both her and the ones she loved suffering.

Thank you for your consideration

Nigel Haines

SUZIE



Explanation of people referred to in this journal;

Mum & Dad – Nigel’s parents

Jon – Nigel’s younger brother

Carolyn, Chris & Si (Simon) – Nigel’s sister, brother-in-law & their son

Joann (Jo) & Barry (Baz) – Long time and very dear friends.

Margaret & Bruce – Long time and dear friends (Jessica their daughter & Nigel’s God Daughter & Ryan, their son)

Scotty & Anne- Long time friends.

Wendy & Aadrian - friends

James (Jim) - Suzie’s ex husband. We became close mates & Linda his third wife.

Pammy - Jim’s second wife who died of cancer.

Pandora & Bernie – Close friends who are/were in the shopping centre industry

Peter – Nigel’s boss

Julie (Jul) - Mandurah Alzheimer’s councilor

Carmel, Helen & Dianne – Carers who used to take Suzie out before she was hospitalised.

Gilly & Jack – Suzie’s sister & brother-in-law living in the UK. We last visited them in Jan ’04.

Lucy & Laura – Jack & Gilly’s daughters.

Jack & Doreen – Friends we met when we first came to Mandurah

Anthony & Bernice – Suzie’s brother & sister-in-law.

– Neuro surgeon at the Neurosciences unit that took on Suzie’s “case” as she was so young.

Fran & Milton – Fran is a long time friend who used to work with Nigel and they live in Mandurah.

Eddie Storm & Vera (Vee) – Eddie is an elderly friend who still sings professionally. Suzie fell in love with “The Phantom of The Opera” Eddie first sang at a Mandurah restaurant in 1999. They have been our friends ever since.

To be quite honest, I really don't know why I'm starting to write this. Perhaps a diary of the Alzheimer's patient's daily experiences to monitor the changes will help someone. However, in the short time that I have seen this tragic disease take over Suzie I know that there are too many variables to be able to really glean information which could assist in predicting what we are in for.

What we do know is that it affects everyone in different ways, some succumbing faster than others. Some people are able to write longer into the disease. Suzie hasn't been able to write her name since early 2005 having been diagnosed with Dementia, probably Alzheimer's, in May 2005.

The only certainty is that the sufferer does not recover and they go down at various degrees, sometimes having plateaued on the way but always, always, finally going into that black abyss.

Perhaps as I continue to type this, the reason or the benefit may become apparent because, although I have some very dear family and friends, I feel less inhibited and feel more able to exhaust some thoughts and emotions than by talking with them.

I think I will firstly give a background to Suzie's illness and then, when fully up to date, use this as a medium to record relevant events or emotions.

It is hard to establish when Suzie first started showing signs of Alzheimer's. We all have, at some time, misplaced things or got up to do something and then think "what was I going to do?" Crikey, I still do. The one incident that sticks in my mind was when I was living in the mobile home in Mandurah and Suzie, who was still living in our house in Kingsley and working in a real estate office in Osborne Park, would come down on Wednesday evening and go back on Thursday morning and then back down Friday night for the weekend and back to work on Monday. We had gone out for a meal and I had asked her, as we always did as part of a routine, to make sure she put the key to the mobile home in the outside laundry.

When we got back it wasn't there and for some reason I was really annoyed saying that she had recently seemed to be in her own little world and she should pay attention. Yeah! Great words of inspiration Nige! But that was all I thought it was. She had said that her boss had been commenting that she had been forgetting things but he himself was unorganised & I said he was probably just saying that to cover up his own shortcomings.

Whilst she was now working as a receptionist PA in a small real estate office she previously had worked as a residential property manager with around 300 properties on her books. She seemed to be able to handle that with ease and was always well organized at everything she put her hand to. Why would I even think that it could be dementia or Alzheimer's? After all she was only 51!

A little later on Suzie's boss told her that he was closing down the office and he was going to work from home so she should look for another job. We later found out it was his way of removing Suzie without sacking her. Hey, it's understandable but all the pieces didn't start to come together for a year or so later.

Now permanently living in Mandurah with me, Suzie took on a temporary role at a chiropractor's but, from the first day, I could see that it wouldn't last as she was saying the chiro kept complaining that she wasn't laying out the equipment, between clients, in the manner he had shown her. After the third night of discussions I could see that the description, of where each item was supposed to be, had changed.

The incidents increased. Now, that's not to say that she was getting worse. I was now noticing it because it was relevant. Just like if someone tells you that there are a lot of VW's around, it then

seems that every second car is a damn VW. Whilst I wasn't becoming paranoid it did seem to occupy much of my thoughts.

In early 2001 we went to the local GP and told him that we were concerned about her short term memory loss. He carried out a senility test which she passed without a problem. Because Suzie had her Thyroids removed in 1997, and was on permanent medication, it was thought that this may be linked to the issue and so blood tests were called for. These came back negative and so the old favourite for all Alzheimer's sufferers was rolled out..... depression. "You are kidding me" I said, in true chauvinistic fashion, "what's she got to be depressed about? We don't have any financial problems. We live in a great town with a great lifestyle. We don't have kids so there's no issues there." A short stint on Zoloft and then back to the doctor's to report that we were convinced it wasn't depression.

With that, the doctor had us off to the psychiatrist. He reported that he suspected that the poor memory is due in part to poor concentration stemming from anxiety. Therefore, Suzie should continue with the antidepressants. At my insistence Suzie was given other tests including Cat scans, MRI and ultrasound. Then, the psychiatrist sent us to a clinical psychologist in May 2004.

This person was a work of art. In a previous life she was a senior member of the Spanish Inquisition. I say this because all the reports we had to date stated that as Suzie became more stressed or anxious the worse she became. However, this doctor, when verbalizing the summary of her 7 page report, on no less than four occasions said "you should be preparing yourself for the worst". I couldn't handle it and told her I believed she was being harsh and that I'd read the report at home and we both left. This was the report that concluded that Suzie had dementia, probably Alzheimer's.

Back at the psychiatrist's we were then referred to the Neurosciences Clinic in Mt. Claremont. The doctor here was a really nice guy. Professional to the point of regimental, but none the less I thought he had a softness about him. Something that the Psychologist could learn from him. At our first meeting I could sense that there was going to be problems with Suzie. Yes, we were still both in denial, me just a little out of desperation, Suzie just denial. Here she was, in yet another doctor's office, about to answer another load of ridiculous questions. (These are the same type of questions she passed in the senility test 3 years previously)

Dr: Suzie, do you know the name of the Prime Minister.

Suzie: No. I don't watch the news.

Dr: Suzie, do you know the suburb we are in at the moment.

Suzie: No, Nigel drove here.

Dr: OK Suzie. What suburb do **you** live in?

Suzie: This is ridiculous why must I answer these stupid questions?

At this point Suzie got up in a rage; I immediately excused us and took her out side in the hall. I really didn't know what to say or do but I begged her to continue answering the "stupid" questions because the doctor was there to help us. I don't think it was the wording of my plea that got through to Suzie but the fear in my eyes and the tears that were rolling down my cheeks.

We went back in and completed the test. I do remember that when asked to write a sentence she wrote "this is a sentence". This sticks in my mind because of the fact that she now cannot even write her name.

Suzie later underwent PET scans which conclusively pinpointed Alzheimer's disease. Just looking at the scans, with the dark voids where only a couple of years ago there were parts of Suzie's brain was almost surreal.

Since that day I haven't been in denial and, over time, I believed my role has been to protect her from anything that may upset her. It is easy for her to get upset, understandably, and it takes me an age to pacify her.

I mentioned the help of our family and friends but unfortunately some have not been as supportive as others. My side of the family has been great although there is very little they can do. Mum & Dad "babysat" Suzie for a week in August 2005, while I was in Melbourne for a conference. Suzie really was getting worse and I wish I hadn't put Mum & Dad through that. Suzie was telling everyone that I wasn't coming home, even though I would speak to her four or five times a day. I later found out that she dreamt that I had gone to war and was killed. The only part of the dream she remembered was that, for some reason, Nigel didn't return. Jon, Carolyne & Chris ask after Suzie regularly and Si has called through a couple of times. As I said, they have all been extremely supportive.

He sent me an email saying that he wouldn't be able to see Suzie again as his wife gives him grief if he does. Jesus! If my partner told me I couldn't visit my even regardless if she was ill, they would no longer be my partner. James and Linda just didn't seem to keep in touch.

From:

To: Nigel Haines

Subject: RE: Suzie

Nigel, i tried to ring sue today but no answer. How is she, when we saw you both at Hillarys she looked OK. Mate I know that I am not in your good books and I am sure that you don't understand why I don't visit more often. i think about Sue all the time and wish that things could have been different. Its probably my fault for letting things get the way they did over the years. That doesn't mean that i don't care about Sue and what is happening. I have to concern myself with as well of course, after all we have been together for I probably should not have ever included Sue or Yourself in any of my problems but if I had gone down that track I would never have had any contact with Sue at all after I will try to call sue more often but i doubt that we will be visiting too much more. it just causes too much grief between me and Say hello to Sue for me will you and I will try to call her again over the next couple of days. See you at wedding.

Dear Dr.

Suzie Haines: Appointment 9/11/05

I thought it advantageous to note down a few points regarding Suzie's condition prior to our appointment.

She has definitely deteriorated with regards to concentrating and even recognition of certain things by word.

Example of this are when we are going out in the car, she will stand next to me as I get in and not realise she has to go around and enter by the passenger side.

When asked to put something away in the fridge, pantry, top draw etc on numerous times she will go to the wrong place.

She usually does not like going to bed without me but last night she said she wanted to go to bed and so I got her PJ's ready for her and she went to bed but within 2 minutes she came out again

and was confused as to why she was in bed alone. I explained to her that it was her idea and she went to bed again. She came out two more times and I put her to bed again. When I went to bed I found her sitting upright waiting for me.

Amazingly she is able to iron my shirts off her own initiative. Get the iron, the ironing board coat hangers etc. Do a good job and then put everything away. She usually does this when I'm at work and so I do not know how long it takes her.

I'm sure you will have questions for me but I thought I would give you some information prior to our appointment.

*Kind regards and sincere thanks
Nigel*

I started writing this in September '05 but it only lasted a couple of weeks as I had trouble focusing as to why I was writing it and it also seemed to remind me about the hopeless situation we are in.

It's now Jan '06 and I feel I should continue because there may be a benefit somewhere along the line. I feel I should just keep it as a journal rather than segment it into various sections covering the numerous aspects of our situation.

Suzie has deteriorated quite a lot since September. I now have to select all her clothes and in some cases help her put them on as she regularly puts on jumpers and pants back to front.

A week before Xmas she roamed for the first time. Carmel, one of her day carers, found her walking the street with a young girl who was walking her dog. When Carmel approached, the girl said that "the lady needed help". Wendy later said that she had a suspicion that Suzie may roam because when she went to collect her, on a couple of occasions, Suzie was in the front garden waiting for her.

*Good Morning Dr
An update on Suzie.*

*Up to now, I have left for work at 5.45am and rang Suzie about an hour before her carers arrived to let her know that they would be there soon.
Yesterday she was found by her carer out in the street, around the corner, and was confused and disorientated.*

I have now arranged with the carers to collect her and drop her back at my office so that she is not left on her own.

Today we had a new carer and so we first had coffee so that Suzie could meet her with me. Unfortunately she became rather agitated when it came time for her to go with the carer. The carer was very good with her though and they went for a drive around Mandurah. She was fine when she returned a couple of hours later and was also fine when the second carer came to take her out for the afternoon.

*Kind regards and have a safe & happy Xmas
Nigel*

Since then Suzie is never alone. I take her to work with me, in the Centre Management office, each morning and the carers then collect her from there and, depending on the return time, either bring her back to the office or drop her home if I am going to be there.

*Dear Dr
I recently wrote to you giving an update on Suzie. I commented that I doubted the benefit of the Ebixa. Today I met with Julie Ploenges from the Mandurah Office and gave her an up date.*

Suzie is now becoming more restless at night and whereas she used to fixate on needing to know that she had her watch with her, it is now her "Bumbag" which contains her mobile 'phone, which she hasn't used for over 12 months and her purse.

Last night when this happened I explained that we had left it at my office and I would collect it and give it to her before she went out the next day. Unfortunately this did not help and about every 10 minutes she sat up in bed and looked around for it. We eventually got to sleep around 2.30am.

I have asked Julie to contact you and discuss the possibility of replacing the Ebixa and perhaps an anti depressant or sleeping tablet to assist with her getting a good night's sleep.

Kind regards

Nigel Haines

I went to Brightwater "The Cove", the residential Home which caters for people with dementia and Alzheimer's. I'm going to have to start preparing for Suzie's future accommodation, as there is a waiting list. Fortunately at Brightwater, when Suzie's name is on the list they contact us when there is a vacancy and, if we are not ready to take it, her name stays on the top.

A few weeks before Christmas, Carolyn suggested that Suzie & I go with them for Xmas Eve to Jim & Linda's. I said yes but a couple of weeks prior to going I realised that it wouldn't take much for me to tell Jim exactly what I thought of the fact that he hadn't rung up to see how Suzie was. I asked Chris to let them know that I didn't want to go through twenty questions when we arrived because my answer would be, "well you haven't wondered up to now so why the sudden interest?" They were the hosts and even though, I believed, they should have kept in touch, I had no right to spoil their Xmas. I still however, expect Jim to ring. I'm possibly being unreasonable as he now, and for some years, has his own life to lead.

Just before Xmas Jim rang me saying he had told the family not to bombard me with questions, and during the conversation said that he "could not deal with Suzie's illness as it was too upsetting for him". He acknowledged that Suzie stayed by Pammy's side throughout her cancer but could not return the gesture. In retrospect I may have been hard on Jim with my comments but that was the way I felt at the time of writing.

I still ring Gilly, Suzie's sister, so Suzie can speak to her & her Mum.

As I said, I still ring Gilly so Suzie can talk to her.

10th January 2006

There are moments when Suzie becomes quite lucid and this morning Suzie was very unsettled and was trying to ask questions about her illness. She eventually said that she was tired of being ill and wanted to go back to the way she was. This communication took around half an hour to understand, as she continues to have difficulty articulating her thoughts.

I did my usual "This is what's happening today" routine but it didn't help. She was asking why she had been "picked" to be ill, if not everyone had the illness. She asked if everyone who had the illness had the same problem. I explained that some people forgot their partners and family whereas we were "lucky" as she still remembered me. She said that she never could forget me,

no matter how sick she became. She was so upset that I couldn't contain my own emotions and I lost it and ended up sobbing uncontrollably.

It was amazing, Suzie immediately took charge and comforted me as if she was back to her old self. Her caring instincts kicked in and she forgot about being sad. Her only concern was for me. After a couple of minutes we just lay in the bed and cuddled. I have major deadlines and a visit from my CEO over the next couple of days and so it's important that I go to the office as usual. It may seem cold but I have to continue working if I am to help Suzie in the best way I can.

The last couple of weeks has shown me I have a long way to go in the patience dept. I know I couldn't care for Suzie 24/7. I need the help of professionals and friends who can remove themselves from the pain. I am so scared that I might end up resenting Suzie and this would be unforgivable.

I can't remember if I wrote about this before, but I use the same "skills" I needed in dealing with as I do with Suzie. It has to be reassuring but not condescending, and strong but not interpreted as bossy. In each instance Suzie's mood could change and so you cannot go too far in one direction lest the mood changes and an issue arises.

For a number of weeks now, Suzie hasn't mentioned the fact that she hasn't driven the car for a long while. I think she finally realizes she no longer has the ability. We still talk about her driving skills. Like the way she could back the huge ski boat trailer down the ramp, put on the brakes and the boat would majestically drift off the trailer. Or when she used to ride the trikes. Especially the big one, with Loretta, our Bull Terrier, harnessed on the back seat with her front paws on Suzie's shoulders.

Joanne, Suzie's closest friend had a health scare and had to go to hospital which meant that the usual trips to Armadale each Thursday are suspended for a few weeks. I've a heap of leave owing and so I'm taking the days off. It's summer, so we can go out on one of the "toys". Suzie still enjoys a ride on the Harley (as long as it's over 25 degrees!) or on George our pontoon boat and she likes going out in the Corvette if the roof is off. We don't speak much as it's always down to me to initiate the conversation, unless she sees something that she comments upon. You have to be able to hear what she says the first time however, because if you say "pardon" she can't remember what she just said. The most common phrase which is used by us both, scores of times a day, is "I love you" followed by a blown kiss.

Around three evenings a week we go to the Offshore Fishing & Sailing Club and have a glass of wine before going home for the evening. Here the conversation is sparse but we always say the same things like "we like it here don't we" or "I don't think we'll ever leave Mandurah, do you?"

Having dined out a lot over the years, Suzie & I used to have a joke about the couples who were at the restaurant but did not speak much. We used to say that they had been married "too long" as they had obviously had lost the power of conversation.

When we used to go out we talked the whole time. About our jobs, politics, forthcoming holidays, family, everything! God I miss that.

12th January 2006

Yesterday I received a 'phone call from Carmel who said that Suzie had collapsed and asked if I would OK her ringing for an ambulance. I obviously did this and met the ambulance at the Peel Health campus. At first, Carmel believed she had a seizure but the tests and further questioning of Carmel indicated that it was a panic attack. I can see when one is coming on, as Suzie's breath

becomes shallow and rapid. I found that the best thing to do is to cuddle her and speak softly about anything positive.

She had an attack the other week when we were out in the boat. Usually a place where she feels relaxed. We were with Scotty, Ann, Kimmy & Aaron at the Ravenswood Tavern. Kimmy had brought some veggie Tofu and had given Suzie a slice when a female security guard came over and told them off for bringing food to the venue. Even though we were sitting on the riverbank right next to the boat. Ann tried to reason with the woman but to no avail. I think Suzie thought she had done something wrong because she went very quiet. As I was driving the boat I didn't notice her breathing but she just started crying. Ann & Kimmy were either side of her and hugged her, which helped, and eventually she calmed down.

Her mood swings need close monitoring. Today, she was getting ready to go out and I, as usual, made out that she had chosen what clothes she would wear and she was in good spirits. I went to get ready myself and when I came out of the bedroom Suzie was looking very nervous. I couldn't work out what happened but it took about half an hour to cheer her up.

One of the difficult things is to get accustomed to her frowning much of the time, although I should be used to it with You think she is sulking but when you speak to her she smiles and is obviously fine. When walking with her she always walks two paces behind. If I slow down so does she. I guess it's so she can see me, I really don't know.

Joann is on the road to recovery and so our trips to Armadale, on Thursdays will start again soon. Suzie really loves Joann, as indeed do I, both Joann & Barry. They are very true and dear friends to us and we are lucky for that. When I collect Suzie from a day with Joann she is always in good spirits. I hate to think how we could cope if it were not for them.

13th January

Last night Suzie told me that she didn't like going to Curves because there was someone there who was not nice like the other ladies. I explained that it was only for ½ an hour every Tuesday and Friday and after her session at Curves she went to Wendy's house. She really likes Wendy although I think that sometimes Wendy reads Suzie's facial expressions as a negative and might, herself, become upset.

Suzie's insistence to have her lipstick with her at all times continued last night when we were in bed. She started to breathe quickly, the indication she was becoming anxious, and was trying to say something. Having established it was her lipstick I told her it was on the bed side cupboard but she insisted she saw it. I got up, turned the light on and when she saw it she was immediately OK. She used to have this issue with her watch but she hasn't mentioned this for quite some time.

Early this morning however, she woke me up to tell me she didn't have any clothes on. I explained to her that this was not an issue as we didn't wear clothes to bed. It obviously worried her because around 5am she started crying. Again this was due to the fact that she felt she should be wearing some panties. I again told her that this was OK but that the next evening I would ensure she was wearing a pair of panties before she went to sleep.

14th January

Suzie had another bad night last night, needing constant reassuring. In the early hours of this morning, still upset, she frightened me. She woke me sobbing and asked me why she couldn't just die in her sleep. This feeling of hopelessness she has, I find, I too am beginning to share. There is absolutely nothing that can be done to alleviate it. I guess she could be drugged up to the eyeballs and sit in the corner like a zombie but is that any way to live?

After Pammy died of cancer, I said that if a doctor diagnosed me with cancer or anything terminal, once I was told I shouldn't be driving I'd "check myself out". Seeing Suzie sobbing her heart out, I can't but think should I be helping her to do likewise? I shouldn't be writing this but I'm just putting down my thoughts. I'm emailing to see if there is any medication that might minimize Suzie's feeling of hopelessness.

Dear Dr.

As discussed, we are cutting down the Ebixa. One tablet a day now for another two weeks. Suzie had a panic attack on Wednesday and I asked the Dr. at Peel Health Campus to send you his notes.

Suzie's anxiety is increasing with her needing constant reassurance. She has a feeling of total helplessness but, whilst we reassure her we are there for her, it doesn't address her fears.

I have always been against anti depressant medication but if this is what it takes to make her feel better, and not suffer as she is, then I guess we should look at that. My fear is that with medication she will become more withdrawn than she is now.

I appreciate that nothing can be done to address the Alzheimer's but is there anything that can minimise her anguish?

Kind regards

Nigel

16th January

On Saturday evening Suzie scared me like never before. During our time together we have never really argued. Certainly not with raised voices or nasty comments. But on Saturday evening around 9.30pm she fell asleep in front of the TV, as she usually does, and so I tried to gently awake her. She woke up startled and said to me something like "Now I know what you are up to". I said "What do you mean?" and she said "Don't deny it". I carried on questioning her but her body language was very aggressive. Hand on hip pointing a finger to my face. She was mumbling incoherently and went around the house looking through the curtains saying "Yes, I knew it" & "Yes, I thought so". This went on for about three quarters of an hour and then she suddenly stopped and went back to her usual self (Usual for how she has become anyway).

As I said, it really frightened me because I could almost see hatred of me in her eyes and nothing I could say would calm her down. I emailed Dr.

Today I completed the application form for "The Cove" the home I think that I will have her admitted to. I felt sick in the stomach as I could see what I am soon to do. I feel so guilty thinking I should be doing more for her but I physically, and mentally have no more to give. I wish that she would stop remembering, or at least having such a dependence upon me. That way it would make it easier for her to be admitted. Is this a cop out by me? I really don't know.

This morning I dropped Suzie off at Curves for her short workout before going out for the day with Helen, one of her carers, but she was only there for a few minutes when I received a 'phone call from them saying Suzie was having a "bad day" and asked me if I could go and collect her. She has to stay fit if she is to slow down the illness. It's hard to see why anyone could get stressed like she does but that is the nature of the disease.

17th January

Yesterday after Helen, another carer, dropped Suzie back at the office I told her I wanted to check on the boat as I had put in new bungs following one of the pontoons taking on water. When we arrived at the club Suzie became very agitated and I eventually found out it was because she had her gym gear on and believed it wasn't the correct attire for the club. This was incorrect as it was only 5pm and there, usually, was only a couple of people in the bar anyway. I

said that we should go home & check on the boat another day. This didn't seem to help because she then believed she was messing me around. Whatever I suggested we did was not right and she continued to be agitated. Eventually she calmed down and we checked on the boat and had a glass of wine each at the club.

At home I suddenly felt extremely lethargic and just laid down on the settee. This is unusual for me and Suzie picked up something was wrong. She cuddled me and we lay together for a while. We discussed, as best we could, what was wrong with me and I was quite candid and said that I was mentally drained and when Suzie had one of her "turns" I had a feeling of complete hopelessness. Just as she had done once before, Suzie seemed to take control and said she would "be strong" for me so that I could help her.

She had a great night; she got ready for bed without a problem and did likewise when she got up this morning. I hope that she is OK at Curves today.

18th January

I spoke too soon yesterday. As we were walking over to Curves, Judy the owner asked if we could delay Suzie attending until 12 noon as they were busy first thing in the morning and couldn't give Suzie the attention she required. I explained that we were on our way and so continued. When I got back to the office I contacted the Alzheimer's Assoc and told them we needed care for Tuesday from 9am to 12.30pm and likewise for Friday's.

Later in the afternoon Carmel rang and said Suzie was getting agitated and insisting she be dropped back at my office. I spoke to Suzie and was at a loss as what to do. Suzie sensed that I was upset and immediately did a turnaround and said she was OK there and would see me at home later. Carmel later confirmed that after speaking to me Suzie was OK

We had another restless night last night. I recall still being awake at 2am. However, Suzie wasn't too bad this morning. I told Carmel the fact that Suzie responds positively if she thinks that I'm the one needing help.

I just rang and spoke to Suzie at Carmel's to give her a "Nigel fix" it seemed to have lifted her spirits. I just said that I'd ring the Fishing Club (I hadn't really) and they confirmed that they had pasta on the menu and that's what I was going to order. OK it's bull dust but it was positive and she got to speak to me.

I have just received an email from at the Alzheimer's Assoc:

Hi Nigel,

You will find the strength and ideas you need to get through this confusing and unstable time in both yours and Suzie's lives, please keep talking to others and documenting your difficult times as you have been as it will help you to get through.

we have advertised in this weeks local for more careworkers with great response, so will soon have the ability to assist you both more.

please remember to consider yourself first in all of this, Suzie will not have your strength and protection if you don't take care of you first.

only in her 20's but a tremendous support.

23rd January

The panic attacks are increasing. Last week, Dr. _____ called to say he had received my email and was arranging for their psychiatrist to see Suzie and they would prescribe something to help her.

On Friday we went over to Barry and Joann's for his birthday celebrations. I really enjoy being with them. They are so supportive of Suzie. Unfortunately on Saturday morning Suzie had a panic attack and we left early and went home. She kept saying, "This isn't right. It's not right" but was unable to expand upon what the issue was. Half way home she came good, again, I think she saw that I too was upset and she started comforting me.

Carolyn & Chris came over for the day and we went out for a meal. By the time Suzie had got dressed and ready to go out she was totally withdrawn. Carolyn commented about the change. But then, during the meal she came good and was quite chatty. I have to help more with her meals now. She was unable to cut her meat. Using the fork as a knife or holding the knife upside down. Sometimes when I help she is appreciative, other times you can see she gets frustrated.

This morning, she was extremely argumentative about what she was going to wear. In the end I said she could wear what she liked because I had had enough. She immediately said sorry and asked for my assistance. Whilst this type of method of dealing with her works, it is totally alien to me. Firstly because we never used to speak to each other like that and, secondly, because I know it's not Suzie acting like that, it's the illness.

She stressed out yesterday afternoon when it became obvious she can no longer iron my shirts. I finished them off but thanked her for doing them and I think she forgot that she no longer has this ability.

We arrived at work and I put the personal DVD on for her and she was singing along with some of the songs. As she sits opposite me whilst I work at my desk I can see her expressions as we blow each other the occasional kiss. For some reason she suddenly stopped being animated and had her "angry" expression on. To ensure she didn't fall into a panic attack I stopped what I was doing and started talking to her about, well I can't remember what but it was just positive things to try to stop the attack. By the time Helen arrived, to take her out for the day, she was not panicking but very "teary". Helen said that last week around 2pm she became upset and wanted to know where I was and she found that by changing the subject she was able to pull her through.

The people I work with are tremendous and a great support. They all are upbeat when Suzie comes in and make her feel welcome. Peter, my boss, is also very supportive. Taller than me, he is a big guy with an even bigger heart.

This evening I have a meeting from 5.30pm for about an hour. I've arranged for Suzie to call in to Wendy's for this time but I haven't told Suzie this yet as she'll only stress as it's something different.

I don't know how I will cope. It's getting so difficult now with her mood swings. I need some time alone or at least away from her. It sounds terrible but I'm so scared I will end up resenting her. I think I'll have Suzie admitted to Brightwater for a week but I'm concerned that, if she hates it, it will make it more difficult when I need to have her permanently admitted.

Chris rang and suggested we get together for a meal to celebrate our birthdays. I agreed that it would be a great idea as we weren't having our usual party. He asked if Jim & Linda could be invited, I said "no".

January 24th

Suzie spent the day with Helen who took her for a walk with the dogs and then went to Lake Clifton and saw the "Living Rocks" she came back very up beat. I had a meeting at 5.30pm for an hour & a half and dropped her off at Wendy's. I was concerned that she may regress but when I picked her up she was still good.

Despite her being in good spirits yesterday afternoon & evening, she had a bad night. Well, we both did. We went to bed early, at 8.30pm, but she couldn't settle. We were still awake at 2am. She woke me at 5.30am to remind me she had to take her tablets when she got up.

She again frightened me, this time by what she said during a teary moment around midnight. She was having great difficulty telling me what was wrong and in a moment of great frustration said she wished she was dead because she couldn't carry on the way she was.

I will email Dr

Good morning Dr.

Suzie's mood swings are more prevalent with her being in good spirits one moment and then confused and upset with no apparent cause/reason. Her ability to communicate is further diminished and we have to give her suggestions as to what she is referring to or trying to say. She no longer can iron my shirts and, at the realisation of this, she became very upset.

We have an appointment with Dr. next Tuesday at 11.15am and I'm hoping he may be able to prescribe something to calm her. I have put her name forward for future admission to Brightwater, here in Mandurah. Again though, I cannot let her go whilst she has so much dependence on me. It would be cruel to do such a thing.

Last night, we went to bed around 8.30pm but she was unsettled until 2am, and she again frightened me, this time by what she said during a teary moment around midnight. She was having great difficulty telling me what was wrong and in a moment of great frustration said she wished she was dead because she couldn't carry on the way she was. I told her never to say that and that Dr had arranged for us to go to see another doctor next week and he would help us.

Suzie is never alone and so the chances of her harming herself are remote. Even so, it is extremely worrying that she has said this. She has always, always, spoken out against this sort of thing saying nothing could ever be so bad as for someone to do self harm.

I will continue to keep you apprised of the situation.

*Kind regards
Nigel Haines*

25th January

I'm really struggling to cope now. Last night we had an early night but Suzie woke up at 4.45am crying and saying she was frightened of the dark. It took around half an hour to calm her and then she was OK again. However, whilst she was having her shower she got upset when she put her head under the water. She became agitated and from then on it was a major job to get her dried and dressed. She was insisting that her panties weren't hers and that her jeans and jumper were on back to front (they weren't).

All the way to work she was shaking and I was considering taking her to the hospital. But what would they do? She'd be stressed out there with strangers. Rather she is uncomfortable with people she knows than stressed out in the company of strangers.

As we arrived at the office she again saw I too was getting stressed she comforted me and said that we should have a cup of tea. Sometimes short sentences come out OK.

I put John Farnham on her DVD and she sat down singing along to some of the songs. I asked her if she needed to go to the loo, before Carmel arrived to take her out for the day, and Suzie's mood changed again, shaking and breathing quickly. She really adores Carmel and her other carers/friends and so it is so puzzling to understand what the issue is. I have however, come to accept that this bastard disease has no rationale or reason.

I'm expecting a few 'phone calls today as I think Suzie will be quite restless. I can't wait for next Tuesday to come, so we can see the psychiatrist and have him prescribe some medication for her. I don't know what I'll do if it doesn't help.

At 3pm on Friday, from the Peel Health Campus is visiting us at home. He is giving Suzie and appraisal with regards to her "suitability" to go to Brightwater.

Hi Nigel,

One of our wonderful councillors from Perth office is coming down to Mandurah for a few sessions next month. He would be available to speak with you for an hour or so, also he would be available to speak with both you and Suzie if you would like.

This is just a suggestion for you both..

Let me know if you would like to see Todd.

Regards,

Hi Suzie is deteriorating quickly now and so I think we will be considering Brightwater soon. is seeing us this Friday and the Neurosciences psychiatrist will be seeing us next Tuesday. I think how long I keep Suzie with me will depend on how she responds to the medication. She was extremely agitated today and I'm expecting a couple of 'phone calls from Carmel for me to reassure Suzie during the day. I've met Todd before and hold him in high regard. I'll let you know how we go with Peter and the psychiatrist.

Regards

Nige

26th January

Suzie didn't panic when she was with Carmel yesterday but when she arrived back home she thought I wasn't here and burst out crying.

We picked up Wendy and went to the Club for tea. Suzie was totally withdrawn until Eddie ("Storm") and Vera walked in. Suzie came good for about ten minutes but then went back to wherever she goes when she withdraws. Just on that "place" Suzie goes, Wendy told me that when she was around her house on Monday she was quite lucid and Wendy asked her if it was a nice place that she goes. Suzie smiled and said "Oh yes, very nice". She had a glass of wine and that might have relaxed her, I don't know.

James rang whilst we were at the Club. Maybe I'm cynical but I'm guessing Chris mentioned something to him. Perhaps I should forget about my negative feelings towards James but it's very difficult for me to do that. He was very supportive on the 'phone saying if there ever was anything they could do, just call him. I was thinking about deleting what I wrote about him earlier in this journal but then it wouldn't be true to the way I was feeling on that day.

This morning I wasn't working and so we stayed in bed until 8am. Suzie was OK right up until it came to having her shower and getting dressed. She again became very anxious and everything I suggested she wear, she said she didn't like. Eventually she got dressed and we went for a drive in the Corvette. We chatted, as best she could, and I said I was looking forward to seeing the

Rocks, that she & Helen saw on Monday, tomorrow morning. We drove up the coast and took in the scenery.

She was great until I saw she was shaking her head and she turned me and with a sarcastic smile and voice said “You’re just hoping they aren’t there aren’t you?” I asked what she was talking about and she indicated, the Rocks. I explained that we were going for a drive today and that we were looking at the Rocks tomorrow and I was keen to see them. She immediately snapped out of her bad mood and agreed that it will be a great day.

Her mood swings are occurring out of the blue and can change back in an instance, just as I have just described.

This afternoon we are going over to Scotty & Anne’s. I hope she is OK so I can relax.

30th January

Had a 4 day break hence not writing anything since Australia day (26th).

We had a great afternoon at Scotty & Anne’s. Suzie however, was very withdrawn but “stable”. She felt at ease there especially as the two dogs were around and were a positive distraction. I wish we still had Zoot although I know we did the right thing. With Suzie not being left on her own anymore means Zoot would be at home on her own and that just wouldn’t be fair.

Friday morning started out well but as we were arriving to pick up Wendy and go and see the Living Rocks Suzie became very distressed and started to cry. We couldn’t get out of her what her problem was. We tried distracting her by asking her about the Rocks but that didn’t help. As we got nearer the turnoff to the Rocks I asked Suzie to help me with the directions. I would ask if we turned here knowing she would say yes. It finally worked and she came good. By the time we arrived at Lake Clifton she was OK again.

At 3pm from the Peel Health Campus came over to do an “assessment” to see what assistance they could give such as shopping etc. It’s only six hours a day and it doesn’t extend to house cleaning or other things, so we won’t be using that. He did suggest that we use the Cove for a weeks respite care, so I could “recharge my batteries”. I’m concerned that Suzie will stress out and so when she is ready to go their permanently she will have, in the back of her mind, a bad experience. I didn’t tell Peter that he is also required to give an “assessment” prior to Suzie using the Cove. I’ll ring him later today.

The rest of the day was good and so we went to the club for tea that evening. Dave Stratton had his huge boat there and he came to the bar to find us knowing we were regular diners. He showed us over the boat but Suzie had to take her shoes off to board it and the marlin board was wet and obviously cold. This caused Suzie to become anxious and I had to calm her down again. It’s like balancing on a see-saw. Always being on the lookout for tale tale signs Suzie might give off indicating she was becoming stressed. You cannot be over complimentary or helpful as she feels it’s condescending and this causes a problem in itself and triggers a negative mood swing.

On Saturday I suggested we drive up to see Mum & Dad in the Exa so we took off the roof and were having a good run until the top radiator hose blew and we overheated. I was concerned that Suzie would stress out (I know I was) but she was OK. I turned it into a bit of a joke and the flat bed RAC truck only took an hour to arrive and took us back home. Saturday evening was OK and Suzie wasn’t too bad during the night.

On Sunday we had brunch with Baz & Jo. Suzie really enjoys their company and it gave me the opportunity to “offload” to Baz. We are indeed lucky to have them as our dear friends. Baz told

me about Suzie getting up at midnight when we were there last and he & Jo staying up until 3am talking to Suzie. She kept saying that she was worried about me. Baz commented about how her articulation had deteriorated and that I needed to take some time out for myself. We are going to see the Psychiatrist at the Neurosciences tomorrow and I pray that he/she will be able to prescribe Suzie some medication that will calm her. If not I don't know what I will do because I know I'm not coping but I can't let her go whilst she remembers me. If I hold on too long I could burn myself out and then Suzie would be taken away from me anyway.

These last four days off certainly demonstrated to me that even if I left my job, I couldn't cope with looking after her 24/7. I'm sure I'd end up resenting her.

We went over to Jack and Doreen for a couple of drinks. Originally they were to come to our house for tea but during the morning I was concerned that Suzie may not be up to it and then they would have to leave early. By going around to their how, if Suzie started to "Sundown" or become anxious, we could excuse ourselves and not inconvenience them. They too have been so supportive of us and it hurts me to see Doreen get upset when she sees Suzie's plight. They are like family to us.

Kevin & Leanne, their son & his wife, were there also. Suzie was very withdrawn and I took the opportunity to explain to Leanne that Suzie wasn't in a bad mood but this was the way she was from time to time. Leanne understood and gave me words of encouragement. Kevin too included Suzie in on the conversations where possible.

I read Suzie's mood and made the decision to go home for tea but Suzie became upset and started to cry. Doreen was visibly upset and I 'phoned her when I got home to explain the reason we had to leave. I picked it correctly. I asked Suzie what she wanted and suggested steak veggies & potato and she said yes. I cooked us the same meal but Suzie was having trouble cutting the steak with her knife and so I cut it for her. I don't know if this is what set her off but she didn't eat any of the steak and I had to throw it away.

When I questioned her as to why she didn't eat any steak she told me that I should know that she isn't a meat eater. This is despite us having this meal at least once a week for the past couple of years. This must have caused something inside her to stay restless. We went to bed at 8.30pm but were still awake at midnight.

At 2.30am I got up and went to the toilet, when I got back to bed Suzie was awake and asked me what I was doing. I told her and asked if she wanted to go to the loo also, she said yes. I pulled back the covers for her but she became angry and asked what I was doing. I told her that she said she wanted to go to the loo but she strongly denied this. I thought that by apologising and saying it was my mistake this would placate her but it didn't. She went right off at me and got out of bed started to shake me. It didn't hurt me but really scared me. I managed to get her back on the bed and basically hugged her until she calmed down. This, I think, was mainly due to me sobbing in desperation. We fell asleep until 5am when she woke up and wanted to tell me that I was sick and that she would look after me. I thanked her and asked if we could just go back to sleep for another half and hour. She started to argue with me again and so I had to get up.

She got showered & dressed without a problem and we went to work. At 8am I received a call from Julie at the Alzheimer's Assoc advising me that Helen's mum had passed away and that she (Julie) was looking for a replacement for the day. She rang back at 9am and advised that she was able to locate someone from 12.30pm to 4pm. I told her that I would keep Suzie with me until noon and then I'd take the afternoon off.

What we really need is someone who can stay with Suzie during the day. Say 9am to 5pm. Use the Exa, if they needed transport, so they can go out and basically "hang-out" together as a couple of friends would. This would be a great alternative to having her admitted to The Cove.

There are two daycare centres in Mandurah, one a silver chain which operates two days a week and one other in Meadow Springs which is one day a week. I checked out the silver chain and they have old people there and I'm sure that would upset Suzie.

Wednesday 1st February
God, what a day yesterday was!

Dear Dr.

Firstly pls thank Mitch for his assistance on Tuesday. It was much appreciated.

Whilst Dr. will provide you with a full report I write to give you further information which I'm sure would also be of interest to Dr.

On Tuesday morning I had a relatively easy time assisting Suzie get ready. She now has a dislike of getting her head under the shower to shampoo her hair. As we were early for our appointment we called into the Oceanus café for a coffee. The view was tranquil as it was on the beach and Suzie was in a good frame of mind during the journey up from Mandurah until half way through her coffee. She, again for no reason, started to shake and then cry. She couldn't explain why and this continued into our meeting with Dr. His report will detail what happened during the meeting.

She calmed down after she took one Alepam, on the way back to Mandurah, and although very quiet was in good spirits. Overnight however, she was very restless. She woke me up by whispering to herself. I understood that she was confirming to herself that there were other people in the house. She got up and went to each room, in the dark, and said "Yep. Yep" and came back to bed. I'm unsure as to why she did this. During Dr. questioning however, he did ask a number of "standard" questions such as "Do you believe that people are after you" and "Do you hear voices". There was a negative response to this, to which I supported. Perhaps Suzie was dreaming about this and on waking up this, for some reason, gave her this belief.

I got her back to bed but she again was anxious as indicated by her short rapid breathing. She explained to me that these people were like her, "ill", but there was nothing to be afraid of and they were welcome in our house. I asked her who they were and she named her carers and friends who look after her. Therefore, not "ill" although I didn't point this out.

Over the next hour and a half she was extremely restless saying that she had no clothes on. I pointed out to her that, whilst she usually wear knickers to bed she, for some reason had taken them off, but this wasn't a problem as I'd get her another pair for her to put on. I did this but she refused to put them on and throwing them on the floor. I went back to bed, but within a couple of minutes, she repeated her concern. I got her knickers for her but she again threw them on the floor. This went on for some time and as she was becoming stressed I gave her one Alepam. About ten minutes later she finally put her knickers on and she immediately calmed down ceased the rapid breathing, went to bed and within minutes was snoring away peacefully.

In the morning she was OK until she had to take her shower, she was restless again and was unsettled when her carer came for her at my office at 9am. Incidentally, on the way to my office, I asked her if she had a feeling that anyone else was in our house and she looked at me in a puzzled manner and shook her head.

Dr has set another meeting for Tues Mar 21st.

*Thanks again.
Nigel*

I haven't heard from Carmel today and so I hope Suzie has been OK. We are going out for tea with Wendy & Aadrian this evening.

2nd February

Suzie came home from Carmel's in a rather anxious state and so I gave her one of her "anxiety" pills. They are rather like sleeping pills. They are to be used as required until her anti-depressant pills start to take effect. Usually around 3 to 4 weeks. I hope they kick in before we are due to fly out to Adelaide for our holidays. The doctors & carers keep telling me I should take a break and to not feel bad about having Suzie in Respite care for a few days. If Suzie hasn't improved by the time we are due to fly out, I think I will take their advice and do this and still go on holiday with Baz & Jo.

I rang Carmel for a debrief on how Suzie was because she was saying things like there were so many people there. There were six for the morning and four, including Suzie for the afternoon. She slept for most of the time. Carmel was candid and said that on the way back Suzie became anxious and Carmel reassured her by saying that they were taking her home and Nigel was there. Suzie said that she didn't want to go to Nigel. I can only think that she had a negative dream about me and she just associated the negativity with me. Who knows? I asked Carmel, probably to ease my own conscience that if I had Suzie "enrolled" into Brightwater, could I be criticised for "copping out too early". She said no and that there were other people at the same "stage" as Suzie. I'm not sure if it helps but at least I know.

After Suzie took the pill we went out to the Club for tea. The pill must have taken effect rapidly as she settled down quickly and was very withdrawn. Aadrian's calamari was served quite a while before ours and Suzie proceeded to, with her fork, drag a heap of calamari rings off his plate, across the table in front of her. She then ate them, off the table, as if they were from her own plate. He was great, he saw the horrified look on my face but without missing a beat he pushed his plate to the middle of the table and invited everyone to tuck in, because they were delicious. What can I say? He is a true mate.

We went to bed by 9pm and, under the effect of the pill, Suzie drifted off straight away, although she refused to take her cardigan off. We had an uninterrupted sleep until around 5am when Suzie started the rapid breathing. She got up and again went around the house in the belief that there were other people there. She wasn't afraid but she seemed to want to confirm her belief. When I showed her that there wasn't anyone there, it didn't seem to matter. Again, when I mentioned this later, she didn't know what I was talking about.

When it was time to get up she again became anxious and required much coaxing to have her shower. I can't just let her do as she wishes otherwise she'd never get dressed and so I have to say things like, "well if you want to go to Jo's then you must have your shower". She doesn't like that but what can I do?

She has spent the day with Jo and I'm just off to collect her.

5th February (Sunday)

I had Friday off as we couldn't get a carer for Suzie. Gino was over from China & staying with Baz & Jo. We had been invited over for the night.

Just as we were about to leave home to go to their place, Suzie had another attack and was refusing to go because "It's not right". She couldn't explain what it was that wasn't right but just refused to go. It took me about half an hour to convince her everything was OK. As I'm writing this in my study, Suzie has come in very distressed and I've had to give her one of her pills to calm her down.

Yesterday, Saturday, the weather was forecast for the mid 30's so we picked up Wendy and went up the Murray River for lunch. On the way back we called in to see Eddie & Vera (Vee). We made arrangements to go to the club on Sunday for crayfish lunch. I realised that I'd have to ask Roger the chef to prepare Suzie's in a simple manner so that she could eat it easily. She was fine until it came time to leave and she started to become teary. Wendy comforted her and we left. We got back to the club and packed the boat away although, Suzie was withdrawn. When Wendy went to get out of the car, at her house, Suzie went to alight also and became distressed when we told her it was Wendy's house. Suzie thought she lived there and didn't want to stay in the car. It was a real job to keep her calm whilst I drove back to our house. I was fearful she would try to jump out as we were going along.

When we got home she refused to get out saying she hadn't seen this house before. I had to go inside and get a photo of her Dad to convince her it was our house. Even when she got inside she wasn't convinced, as we had to go into each room to see if anyone else was there. I asked her if she wanted a tablet to calm herself down but she refused saying she wanted to try to do it without one. We sat on the couch for some time and she calmed down without one. During the night however, she was very restless and became anxious and I gave her a pill.

As I just mentioned, Suzie had another panic attack and I've put her back to bed. I'll tell Eddie & Vee that we can't make lunch.

I now have to take showers with Suzie as she hates it and just sobs the whole time.

7th Feb 06

Hi

Thanks for all your help yesterday. I'm sorry to have burdened you. Suzie has deteriorated further this morning and broke down crying as she didn't want to have a shower. I had to take her in the shower with me again. It was heartbreaking washing her as she sobbed. It truly is an evil disease. Thanks again for your help
Love Nige

Hi Nigel

I am so sorry to hear that, we had a little bit of sunshine yesterday when some of the silly things I did made her laugh, even though she may not remember it was so nice to hear her laugh and we enjoyed her company.

Sharing is never a burden Nig, that's what life is about.

A long time ago a special lady in my life told me that, a second of happiness is more precious than we are able to realize.

Take care Nig and lots love to Suzie.

Love

9/2/26

Hi Dr.

Dr. was questioning Suzie about thinking people were after her or talking about her. At that time this wasn't the case but yesterday afternoon following another panic attack at our friend's house, she

sat me down on the bed and was trying to say that she hadn't done anything wrong when she looked over my shoulder and said "Excuse me I'm talking to Nigel". There was no one else in the house.

Also, now she refuses to have a shower or get dressed and it takes around an hour to wash her standing up and then get her dressed. She also refuses to wash her hair. I get her to join me in the spa in the evenings and so that helps and I'm taking her to the hairdressers this morning to have her hair attended to. She's OK with this idea.

Last night she refused to take of the blouse she wore during the day and this morning she refused to take it off. Again, it took around an hour to get her washed & dressed.

I am talking to Brightwater to see when they can admit her as a resident as I am unable to continue caring for her.

We have another appointment with Dr on 21st March.

*Kind regards
Nigel*

12th February

Last night during one of Suzie's more lucid moments whilst we were lying in bed she broke down sobbing and begged me to help her by not letting her wake up in the morning. It was tragic and I felt so helpless. I counted the number of sleeping pills but whilst there might have been enough for one, there certainly wasn't enough for both of us. I couldn't do that and carry on by myself.

13th February

Putting us both out of our pain has been playing on my mind all day today. How should I do it? On the Harley? In the car with a hose pipe.

*14/2/06
Hi*

Jenny from Brightwater rang yesterday and said that they can take Suzie for respite care for a few weeks. I need to have re-evaluate Suzie this Thursday.

This will mean Suzie can be at Brightwater as soon as a couple of weeks and stay there until I return from Adelaide on 20th March.

This will give me an opportunity of getting my head together and, providing she hasn't deteriorated further, look at any opportunities of having carers from your organisation during the day rather than have Suzie admitted to Brightwater permanently. I naturally want to keep her with me as long as possible.

Dianne is a very nice lady. My Mother commented that she showed a lot of compassion & understanding towards Suzie. As do you, & all your ladies that have helped Suzie & I.

I'll keep you posted and, as always, sincere thanks for your support.

Nige

Suzie has been admitted to Joondalup Hospital's psychiatric ward after a nasty turn.

***From:** Nigel Haines*

***To:** Antony Milford*

***Sent:** Wednesday, February 15, 2006 11:08 PM*

***Subject:** Suzie*

Hi Guys,

Gilly, thanks for being supportive on my way back from the hospital. Whilst I have the support of family & friends over here, it is reassuring to know that Suzie's blood also believe that I'm doing the right thing by her.

I thought that I would have an early night tonight and so turned in at 8.30pm. I got up a little after 9pm and am still pacing the floors. It's around 11pm now. I can sleep soundly when I'm away from home, on business, but it's been a few years since Suzie was away from home without me (visiting you guys in the early 90's). Now I know how she might have felt. It's just not the same in your own bed without your soul mate.

I left Suzie at the hospital and they have said I should stay away for about 48hrs, as this will give me time to get my head together, but I'm already dreading another night on my own and I haven't even been thru' one night yet.

*I had thought about having a few drinks and unwind (Hey Jack, maybe I'll break up a few fights - Not) but I just wasn't in the mood and, they do say, if you drink alone it's the first sign of..... Oh Christ, I'm an Aussie we're all p*sspots.*

I'm trying not to think too far ahead as I don't think it will help but, then again, I've always needed to have a plan (regardless of how dumb it was), of sorts, to keep me motivated.

These last few weeks have been tortuous. I'm a control freak (as you know) and the only thing worse than me not being in control, is having no one in control. This is what it's been like recently. Hopefully, they will look after my baby, to the extent that I can be with her a little longer and with some dignity, that I know with all my heart, she deserves.

Please excuse the ramblings of a lonely insomniac. I think I'll have another attempt at trying to get some sleep.

Take care and love each other like it's your last day together.

Nige

Today rang me and gave me a hard time for not keeping him in the loop.

From: Nigel Haines

Sent: Monday, 13 February 2006 14:53

To:

Subject: Re: Suzie

How dare you have the audacity to ring me after all this time and tell me I should be giving you reports on how Suzie is. I haven't heard from you in nearly a year and after your email telling me that you wouldn't let you visit because it will cause a problem, I really don't give a damn what you think of me.

Also, your claim that you have left "numerous" messages at my office, to return your calls, does not carry any weight. I asked all my staff if they had received any calls from a and they all said no. And honestly, I'd believe them over you.

Please also bear in mind that you can call me at home as my evening social life does not take me out of the house, in addition, there is the email to which you seem to think I should have been using to give you a blow by blow account of Suzie's condition. I have received nothing from you.

situation is sad, really sad, but at least you get to spend the rest of your lives together. I am about to lose someone whom I have grown to love dearly and have never had an argument with.

You & really should appreciate what a blessed situation you have, instead of trying to pass on your guilt and dysfunctions.

Now F off and let me say goodbye to Suzie with some dignity.

Nigel

From:

To: Nigel Haines

Sent: Monday, February 13, 2006 3:05 PM

Subject: RE: Suzie

Believe what you will. However I have been dealing with people for a very long time who will cover up mistakes. I will have to live with my own guilt, something that troubles me daily and which I am sure makes you feel much better. Yes I let Suzie and myself down, however regardless of what you think of me i still love and am upset to know that I have probably contributed to her not knowing who I am anymore. If you have been blessed with never arguing you are one of the lucky ones. I will leave you alone but only as a matter of the deepest respect for Susan. I won't stoop to the level of semi-quoting expletives.

Regards

From: Nigel Haines

To: Antony Milford

Sent: Thursday, February 16, 2006 11:48 PM

Subject: Suzie

Hi Guys

Sorry I missed you Gilly. Suzie's carers rang me three times today to calm Suzie down.

Apparently, after each time I spoke to her, she laid back and had a nap. The doctors say we need to come to terms with the fact that she will not be coming back to us, as she used to be. I am conditioning myself to this, but really am unsure as to what I should do. I got home from work and everywhere I looked I saw Suzie.

I saw her lipstick and broke down, knowing that I would never here her say "Don't do that, because I'll smudge my lips".

Last night I laid in bed just waiting for her to reach across and rub my arm and say "I'm so sorry. I love You". Something which was becoming such a bind for me. Now I long for her touch, or just her breath on my cheek just to let me know that she is there with me.

As I spoke to her today I realised that they had changed her medication as her speech was slurred and she was harder to understand. I am wondering if this is what she will be like when they tell me I can take her to the nursing home.

I have my family with me but I feel so alone, I really don't know what I should be doing for my baby.

I feel so hopeless, just telling her that she should do what the nice ladies asked her, because they will help her get better.

Gilly just rang me.

I really appreciate the support you guys (in the UK) are giving me. This is my first birthday in 24 years that I haven't been celebrating with Suzie. We became "an item" in Feb 1984 and we were looking at the photos only last month.

Gilly, I'm going to the hospital on Saturday but I don't know if they will let me see Suzie, as they are trying to ween her off me so that she is not so dependent on me.

Take care.

Love

Nige

Friday 17th Feb

Hi Guys,

I drove up to the hospital today but the Drs recommended against me going in to see Suzie as she was settled and they were concerned that when I left her she would become anxious again.

They asked if I appreciated the fact that I would not be able to bring her home with me again, as she would need to go to a nursing home when she leaves the hospital. I acknowledged that I did, but on the way back home it hit me.

Mum & Carolyne (my sister) will visit Suzie on Sunday when, according to the Drs, Suzie will be more settled, as the "medication will cut in" .

Would you believe that Suzie's wedding dress is still hanging up in our walk in robe? I didn't, until Suzie wasn't here.

Take care

N

21/2/06

Thanks Gilly,

I saw Suzie today. I wept when I saw her sitting on a chair with her hands between her legs all hunched over.

She recognised me and tried to smile. She is so confused and the medication keeps her in a zombie like state.

This is what's planned:

We have secured a permanent place in a great nursing home but she must be admitted on Saturday so that she has a room allocated.

As the tests at the hospital won't be done until next week, I'm taking her from the hospital to the nursing home on Saturday and then back again on Sunday. That way she is registered to that home and short of inciting a riot, she can't be kicked out. (I was later to regret this throw away line!)

Next week the brain scans will be done. This will give them an insight as to what else has gone wrong to cause such a drastic decline in her condition. It may be possible to address the problem if it is treatable in so much as her anxiety. It may also assist in giving a prognosis as to what quality of life and longevity she can expect.

I'm not concerning myself with that yet as I'm only interested in the fact that I can spend much more time with my baby. Hopefully she will be well enough to be taken out on the boat and visit friends.

I'm not getting my hopes up though.

Take care & much love

Nige

3rd March 2006

Since sending this email to my boss the following has happened.

Received a call from Peel advising that their social carer arrangement (similar to Joondalup's 24/7) did not cover after 9.30pm and if, "in the extreme circumstances", Suzie became violent, would I give them permission to use padded hand and ankle cuffs. On the basis that it would minimise the risk to Suzie, and having no other alternative, I agreed.

30 minutes later I received a call from Peel advising me that they had four staff members restraining Suzie and were attempting to administer sedatives directly into the blood stream. They had called for an ambulance and she was about to be transported to Fremantle Hospital, Psychiatric Ward. At the moment I'm unsure as to what they intend to do with Suzie because Fremantle is not equipped to handle ongoing "violent", yes they now class Suzie as a "Violent", patient. Unless they can stabilise her within an acceptable time" (who the hell knows what that means) she will be going to Greylands. Not exactly the place that we thought that our baby would be seeing out her Autumn years.

Nigel

----- Original Message -----

***From:** Nigel Haines*

***To:** Peter Pike*

***Sent:** Friday, March 03, 2006 2:56 PM*

***Subject:** Suzie*

Hi Peter,

When the ambulance came Suzie woke up from the previous sedative she was given and started throwing punches again and became extremely violent.

This was caused by the hallucinations. It took five of us to hold her down whilst one of the ambos administered the injections. That wasn't enough and she needed a stronger one into the vein to enable us

to strap her down in the gurney. She was screaming thinking we were trying to hurt her. She's covered in bruises, as are the three carers that she fought an hour before the ambos arrived.

I've just left her after two & a half hours in the Peel Triage. They are seeing if they have the resources to admit her to Peel if not I'm concerned they will admit her to a Govt mental institution and so I've begged the Neurosciences Unit to become involved and let me pay for her to go back to Joondalup.

I'm back in the office waiting for a call from Peel.

Nige

From: Nigel Haines

To:

Cc:

Sent: Monday, March 06, 2006 6:21 PM

Subject: Re: Suzie

Hi

Suzie is at Fremantle Hospital Ward F 6 if you call 9431 3333 and ask for the ward they will put you through and advise you if it's OK to see her. In most cases it will be OK.

We are just waiting to see when she will be going up to Joondalup but don't hold back for that. Go and see her as soon as you can. If she plays up when you leave so be it. They are pumping her full of sedatives and so one more occasion won't be an issue they will take the opportunity to bathe her or take some more tests anyway.

Nigel

----- Original Message -----

From:

To: Nigel Haines

Sent: Monday, March 06, 2006 11:47 AM

Subject: RE: Suzie

Nigel, I have been extremely busy since your first email so I apologise for not replying. I can see from the reports that things are getting much worse for Sue, I agree, not the future I would have expected. Given that it seems to upset Sue when she sees people and then they leave, I don't want to compound that for you or her. I think it would be better that at this time I don't make any arrangements to see her, just in case it upsets her and causes both of you problems. I can't put the right words together to relay to you the situation that I am in and I understand that you probably don't understand how I could have left it so long to see Sue. unfortunately that's the situation. I don't envy your position and hope that things improve, I know stupid thing to say. I hope you accept what I am trying to say. If you think that it would be better for Sue that I make arrangements to see her then I will, I'll suffer the consequences. if not i understand.

From:

To: Nigel Haines

Sent: Sunday, March 05, 2006 11:11 PM

Subject: Re: Fw: Suzie

Hi Nige,

It's Sunday i have just read your last email.I take it Greylands is the Gov.mental institution you refered to?

I am so sorry things are still deteriorating, I cannot imagine how hard this is for you to deal with. Gill told me of your telephone call and your concern that you have let Sue down. You must realise that everything you have done is for the best. I think you should take the break that you

have booked otherwise your health is going to suffer from the strain of all this. I know you will not stop worrying about Sue but being away from the decision making for a while might help you to get through this.

You have no reason to feel any guilt whatsoever Nige, please look after yourself and keep in touch.

thanks

5/3/06

Nigel

>

> What heartbreaking news, I am so afraid for Susie, my god what the human spirit has to endure, surely there is no more for her to bear.

>

> Susie is such a gentle spirit, why does she have to endure this terrifying nightmare.

>

> One simply cannot comprehend the pain, emotion and confusion Susie is being forced to endure

>

> I do not pretend to understand such a horrific disease and cannot accept what is,

> I pray that with all my heart my dear friends that you have the strength and

> much love from everyone to get through this time.

>

> Love

>

>

18th March 2006

I arrived back from the houseboat holiday today. Whilst the holiday did me some good unpacking for one brought back the reality of the situation. Whilst I was away Suzie was moved from pillar to post. Dr assured me he'd get her to Joondalup as soon as there was a bed available. This happened on Saturday 11th but they then shipped her out on Monday. Not back to Fremantle, as there was no space there, to Bentley, where she spent a couple of days before going back to Fremantle. It would have been hell for her. They would have had to sedate and possibly restrain her for the ambulance rides.

From: *Nigel Haines*

To:

Sent: Sunday, March 19, 2006 5:42 PM

Subject: Suzie

Today I went and saw Suzie for the first time in 10 days. It was gut wrenching. She looked so old and haggard and shuffled along.

I couldn't keep the tears back and it took a few seconds for her to recognise me. She had a black eye from one of her violent bouts last week and she moved the top half of her body rather than turn her head at the neck.

She is now under the WA Mental Health Act which, whilst a formality, confirms that they can hold her against her will. At the last hospital she assaulted another patient.

I spent just over an hour with her walking around the small garden they have and sitting for a few seconds before she would get up and gesture to me to do another lap.

She mumbled most of the time and it was extremely difficult to understand what she was trying to say. Strangely, every time we sat down she looked at me and with a feint smile said "I love you".

I'm going up tomorrow to see her again and meet her latest doctor.

Like I don't believe in God but if there is one, we should all pray with all our hearts that he takes our baby really soon because it must be a hell on earth for her here. If he doesn't, then there is proof that & I are right.

I will never, ever, forgive myself for not doing something when I had the opportunity.

Take care

Nige

From:

To: Nigel Haines

Sent: Monday, March 20, 2006 5:02 PM

Subject: RE: Suzie

Thanks Nigel, I will go and see her at the earliest possible time I have, I owe her that much.

Sometimes I wonder what it's all about, there must be some purpose in this, I just wish I could understand

Regards

From: Nigel Haines

Sent: Monday, 20 March 2006 16:26

To:

Cc:

Subject: Re: Suzie

Went and saw the Psychiatric team today and in a nutshell:

- They asked if there was a DNR (Do Not Resuscitate) in place. I confirmed there was and referred them to the notes provided to the previous hospital. They asked to what extent it should go I said as far as the law would allow without anyone getting into trouble. They understood where I was coming from.
- I confirmed that it was Suzie's wish to be an organ donor and that if she passed away and five other people were given new leases on life she would be very happy.
- She doesn't realise how she looks and so she still has that self esteem.
- She has moments of aggression but more moments of loving. She would go up to one of the nurses and give them a hug.
- When she becomes aggressive they simply put her in her room for half an hour and it passes.
- She will be in Fremantle for at least another two weeks and so we may possibly lose her room at The Cove. I won't start panicking yet as we still have 5 weeks.
- During a lucid moment today she put her hands to my cheeks and said "How could you let this happen?" I knew what she was referring to hence my stance on the DNR status.
- When I left her today she was a little upset but then came good. even if she does have a lucid moment whilst you are there, and then becomes upset, I would still ask you to visit her one last time.

Will keep in touch.

Nige

21/3/06

I found Suzie's Bum bag in the ute today. It contained her house keys credit card, membership to the Yacht Club, old mobile 'phone and some money. When I go to the hospital this afternoon I'll

ask them if it's Ok to let her have it. She used to like fidgeting with it. I'm also taking the portable DVD so Suzie can watch the Main Event with Anthony Warlow, John Farnham and Olivia Newton John. She loves the opening number and the Phantom theme.

This last week has been horrendous. I'm totally drained and have no idea what I am to do. At the weekend I recorded a "farewell" message on my video as I was planning on "checking out". I was stone cold sober and very calm. It was almost as if I was planning a project for work. Making sure everyone knew what to do and where the paperwork for various things were. I know it's not the answer, but I have a total feeling of helplessness.

Email sent to numerous friends & colleagues on 19/05/06

Pls excuse this generic update regarding Suzie however, with so many people asking after her, it is the most efficient way of passing on my thanks for your kind wishes and enabling me to give the update.

As many of you would be aware, I had to let Suzie go on 15th Feb this year when she was admitted to Joondalup Hospital because the carers were no longer to handle her at home as she was going thru' the violent stage of the disease. Usually this can be handled because the patient is normally elderly however, as you all know, Suzie is/was extremely fit and strong and this caused major problems.

In the next few weeks she went to various hospitals but they were unable to handle her and so she was admitted to the secure wing of Fremantle Psychiatric Hospital where she remains today.

Because of her violent tendencies (this is the lady with whom over 22 years I never had an argument or ever heard her raise her voice in anger) she was put on a number of different medications. Each time she calmed down the doctors would cut back on the medication to see if her condition had improved or if it was just the medication calming her. On each occasion so far, she became violent again. The problem was that it then took between 1 to 2 weeks for the medications to calm her down again. Thus she was going thru' torture every few weeks.

She hasn't recognised me for some time now & I see her for about 1/2hr a week. It is a gut wrenching experience I wouldn't wish on anyone. Seeing the person you love so much, either with shoulders hunched over pacing the ward or, if she has been sedated after an outburst, curled up almost in the fetus position in a chair.

The latest round of medications has caused back spasms meaning she was in pain for much of the time. Yesterday the hospital rang and asked my permission to put her on some very strong medication. What was I to say? I'm not a doctor but if it meant that if it made her more settled and improved her quality of life then do it. Don't even ask; just tell me what has been done.

They now say that in addition to Alzheimer's Suzie is having psychotic episodes whereby she sees and fears for things that aren't there. Therefore, she is in a constant state of agitation and this can easily escalate into violence. For two weeks now, she has had a nurse with her, one on one, throughout the day. All her furniture has been removed from her room and she just has a mattress on the floor.

Knowing Suzie's strong beliefs about quality of life, yesterday's conversation with the doctor arrived at the inevitable question regarding what they believed the future held for her. I was told that they hoped that this new medication would take effect and she would be calm. Being calm also meant that she would just enter a twilight state where she just sat for most of the time and would be "exercised" by the nurses from time to time. If the medication didn't work then they would continue to try other medications in the hope that she could be calmed. During this conversation with the lady doctor, a couple of times, she had to compose herself which tells us about the passion and care that these doctors have for their patients.

I told the doctor that knowing the active, alert and vibrant person Suzie was, I could not help but feel that if she knew how she would end up she would never forgive me for allowing this to happen. I was told that this is a common feeling which, I guess, is cold comfort but accepted.

I asked how long we could expect Suzie to endure this living nightmare. 5, 10 or 15 years?

The response was like a double edged sword, so sad but with a sense of relief. I was told if she was "really unlucky" she would have to endure another 5 year but it was more likely to be 2 years or even as short as 12 months.

Many thanks again for you support I consider myself extremely lucky to have friends and colleagues who genuinely care about us both.

Nige

Dear Nigel

I just cried reading your email.

I am so dreadfully sorry for you and Suzie. It is just so awfully sad and so very, very unfair for you both.

I wish you strength to handle this and I wish Suzie peace and as much quality of life as possible.

Best wishes to you both.

Dear Nigel,

*thank you for letting me know. Hard to type through the tears. I don't know how you cope. I pray for a swift release. If you need a coffee or a hug let me know ,
fondest regards*

Nigel,

Thank you for your update and I can't begin to tell you how my heart feels for you both. Even though I am not big on religion I have started to pray that Suzie and you both are released from this horrific nightmare. The world is definitely not fair on some things.

Keep smiling that great smile of yours when you can and you know we love you and are there for you.

Love you always

xxxx

5/6/06

Today when I visited, Suzie walked for a few paces and then curled up on the floor in the fetal position for a couple of minutes, then got up and repeated this for the 15 minutes I was with her. She has had four sessions of the ECT (Electro Convulsive Treatment). I looked it up on the net and although it still has a stigma similar to the electric shock treatment it has widespread support. For 1 in around 10,000 there can be side effects but these are what Suzie already has ie short term memory loss. It's worth it just to try and have her be rid of the violent tendencies. I kissed her head and she became angry. I try to avoid doing anything that will upset her but if something interrupts her "routine" or you try to get her to do something she's not happy to do, she can become distressed. She is in a permanent state of angst.

I spoke to my family and Gilly about moving on with my life and they all agreed that it was overdue.

7/6/06

I haven't written anything for a while now but after I met with Paula from Alzheimer's, who is writing a thesis on carers, I thought I'd keep it going. I guess the reason I haven't written anything is the fact that Suzie is in hospital and I only see her for between 5 to 30 minutes a week. The email below describes the situation. I had some really wonderful responses from people who are genuinely concerned for Suzie and me. I am fortunate to have these people to call friends. I even received a personal message from the Mayor of Mandurah Paddi Creevey.

8/6/06

Good morning Nigel,

I am sorry I haven't replied earlier, I did not return to the office yesterday and have come in this morning.

Firstly I want to thank you for your time and effort yesterday – I know it was not easy to say the least. It does pain me to now know that it took longer than normal to cover things over. Was there something particular about yesterday that happened that triggered this?. I wonder whether it is too early to ask whether you would like for me to come for a counselling session?

It is good to read that you are starting up the journal again – I can see that it has provided you with much comfort in the past and hopefully can do the same now. At the very least it allows you to write down the thoughts and events that are happening instead of keeping them forever swimming around in your mind.

29th October 2007

It's been well over a year since I wrote in the journal. In December 2006 I was lucky enough to get Suzie admitted to the Greenfields Aged Care Facility just up the road. They too are wonderful people. Suzie cannot speak at all now, she just mumbles. On a good day she will shuffle for a little while but mostly just curls up in a chair. Her head sits listlessly to the left with her chin on her chest. She looks so old now and obviously not the shadow of my darling wife.

A couple of weeks ago she went through a stage of not eating or drinking and the nurse prepared me for the worst but Suzie "came good", if you can call it that and is now eating and drinking again.

This journal was written to help me cope with this terrible situation and I feel it has however, I think it best that I stop now as I cannot see there being anything more to add other than when my poor baby's anguish ends once and for all. To all my friends and family I give my sincere thanks for your support as I know I truly could not have coped without you.

Nigel

Suzie passed away at 3.45am on 9th May 2011 at the Greenfield's Aged Care Facility.

Let us choose

I HAVE just lost my loving wife to Alzheimer's.

She suffered terribly for more than seven long years, the last five being in care due to the severity of her condition.

She was still in her 50s when she passed away, but right up to when she went into care she would work out, in the gym, at

least four times per week.

Her strong heart was what was against her being able to pass away years earlier.

Whilst all other parts of her body were shutting down, her heart would not allow her to pass away.

She was a strong believer in organ donation and the right to choose when she would say goodbye to her loved ones.

Sadly, because of our laws, she was unable to experience either belief.

Like so many others who have experienced seeing a loved one pass

away, in such tragic circumstances, I call upon our law makers to allow us the right to make such a choice for ourselves.

Now, before I'm inundated with condemnation from Right To Life supporters saying I'm misguided, I say this to them.

If you have walked in our shoes, then I respect your views but please do not tell me how to conduct my life.

How I leave this earth will not affect you in one iota.

Continued page 12

from page 4

If you have not walked in our shoes you merely have an opinion, but no experience.

The difference between pro-euthanasia and right for life is simple.

One is stating a view that asks for a choice, for themselves.

The other is forcing a view, and an outcome, on someone else regardless of their views and, in most cases, forces them to die in pain and without dignity.

If the right for life groups want to show they have any compassion all they have to do is respect the wishes of others and focus their energies into areas which do need third-party intervention.

In the meantime our politicians should have the strength to accommodate the wishes of individuals who want the right to choose when to say goodbye, with dignity.

*Nigel Haines
Mandurah*